THE OCCASIONAL PRACTITIONER'S GUIDE TO END OF LIFE DECISIONS

Michael F. Klein, Esq.
Musick, Peeler & Garrett
(619) 525-2521
m.klein@mpglaw.com

David M. Vukadinovich, Esq.
Foley & Lardner
(310) 975-7926
dvukadinovich@foleylaw.com

I. THE LEGAL FRAMEWORK

A. Patient Self-Determination Act (42 U.S.C. § 1395cc(f) and § 1396a(w).)

B. California Health Care Decisions Law (Probate Code §§ 4600-4805) (Added by AB 891 effective 1/1/00)

C. Advance Directives (Probate Code § 4670 et seq.)

D. Powers of Attorney for Health Care. (Probate Code § 4680 et seq.)

E. Request to Forgo Resuscitative Measures ("DNR") (Probate Code § 4780 et seq.)

II. GENERAL LEGAL & ETHICAL POLICIES

A. Competent adult patients may direct the withdrawal or withholding of life-sustaining treatment whether or not their medical condition has been diagnosed as terminal. Qualified surrogate decision-makers may direct such withdrawal or withholding for incompetent patients in appropriate circumstances.

B. Persons who are unable to give informed consent have the same rights as do persons who are able to give such consent. These rights may be exercised through an appropriate surrogate. If no surrogate has been legally appointed (an agent or surrogate designated pursuant to the Health Care Decisions Law, a court-appointed conservator with power to make health care decisions, or a parent or court appointed guardian for a minor patient), immediate family or significant others may be appropriate surrogates. A surrogate should decide in accordance with the patient's wishes, if known. If the patient's wishes are unknown, the surrogate should act in the best interests of the patient.

C. Parents and legal guardians generally have the right to consent to, or refuse, medical treatment for their minor children. However, a mature minor (*i.e.* a minor who has some degree of understanding of his or her medical condition and course of treatment) should be a part of the decision-making process to whatever extent his or her abilities allow. A parental decision to forgo life-sustaining treatment for their minor child should be followed unless there is strong evidence that the parent(s) are not acting in the best interests of the minor. However, life-

sustaining treatment should not be withheld from a mature minor unless the minor and the parent(s) or guardian agree.

D. Life-sustaining treatment, including a mechanical respirator or ventilator, need not be continued solely because it was initiated.

E. In terminally ill patients, medication may be given as indicated for pain or discomfort even if it may tend to hasten death, but must not be used with the primary intent to cause or hasten death.

F. Weighing the Benefits and Burdens of Life Sustaining Treatment

1. Patients and legal representatives considering whether to withhold or withdraw life-sustaining treatment should assess the treatment's expected benefits proportionate to the burdens to the patient. The patient's physician(s) should assist the decision-maker in this assessment.

2. The treating physician, and consulting physicians as deemed appropriate by the treating physician, will be responsible for determining the patient's competence, prognosis and diagnosis, and for providing the patient or the appropriate surrogate with the requisite information to enable him or her to evaluate a treatment's benefits and burdens.

3. Proportionality

(i) A determination of proportionality requires an evaluation in each case of the expected benefits and burdens of the treatment(s) in question.

(ii) The unique facts of each case must be considered. The relevant considerations include:

(a) how long treatment is likely to extend life and whether it can improve the patient's prognosis for recovery;

(b) what the nature of the patient's additional life may be, the possibility of the patient's return to a cognitive, sapient life, and of a remission of symptoms enabling a return toward a normal, functional integrated existence; and

(c) the degree of intrusiveness, risk and discomfort associated with the treatment.

4. Any one particular life-sustaining treatment may not be disproportionate for a particular patient, while other such treatments may be too burdensome. For example, routine intravenous antiarrhythmic medications may be determined to be appropriate for a patient while chest compressions or intubation may not.

5. A competent adult patient has the sole right to decide whether the burdens of life-sustaining treatment are disproportionate to its expected benefits. If the patient is incapable of making the decision, the patient's health care providers and legal representatives must act in accordance with the patient's expressed wishes, as discussed below, or, if the patient's wishes are unknown, must act in accordance with the best interests of the patient.

6. The physician should determine, on the basis of his/her knowledge of the patient, in consultation with family and significant others, and any written documentation, whether the patient has expressed a desire to have life-supporting measures applied under all conditions or a desire to not have his/her life artificially prolonged.

7. If it is determined that the patient has expressed a desire to have life-sustaining measures applied under all conditions, an order to withhold or withdraw life-sustaining treatment should not be issued unless authorized by a court. This policy should not be interpreted to require the provision of care that is determined to be medically inappropriate or futile, however.

8. If the patient's wishes are not known, the legal representative shall act in the patient's best interests. In general, treatment should be provided unless the benefits to be gained are outweighed by the burdens to the patient from the treatment. This determination depends upon factors unique to each case. Factors to be considered in determining what actions are in the patient's best interests include:

(i) the relief of suffering;

(ii) the preservation or restoration of functioning;

(iii) the quality and extent of life sustained; and

(iv) the degree of intrusiveness, risk and discomfort associated with the treatment.

9. Whenever possible, the patient's immediate family and, in appropriate cases, significant others shall be consulted, and their wishes should be given great weight in arriving at the decision. However, the patient or the patient's legal representative must consent to the disclosure of medical information to family and/or friends.

10. If withholding or withdrawal of treatment is appropriate, but a family member or significant other disagrees, hospital administration shall be contacted, and it shall be determined whether court authorization for the issuance of such an order should be sought.

G. Making the Decision to Withhold/Forego Life-Sustaining Treatment

1. The patient shall be the decision-maker whenever possible. However, even when a patient with capacity to make health care decisions has directed the

withholding or withdrawal of life-sustaining procedures, it is advisable to consult the patient's immediate family. (Note that a competent patient must consent to the disclosure of medical information to family and/or friends.) Life-sustaining treatment should not be withheld or withdrawn if a family member disagrees unless the patient clearly has capacity to make health care decisions and the patient has expressly given an informed refusal for the treatment. Such a refusal of treatment should be documented in the patient's medical record.

2. The primary physician is responsible for determining the patient's prognoses and diagnoses and providing the patient, the patient's legal representative, or surrogate decision-maker with the requisite information to enable him/her to evaluate a treatment's benefits and burdens.

3. A patient with capacity to make health care decisions may direct the withholding or withdrawal of life-sustaining treatment after he/she has been informed of his/her diagnoses, prognoses, the nature of the treatment, its expected benefits, its associated risks and complications, and any alternative treatments and their benefits and risks.

4. Confirmation of a treating physician's determinations is not required. However, a physician may choose to secure a second opinion or to consult an ethics or review committee regarding the case whenever he/she determines that such a consultation may help clarify a patient's medical condition or substantiate a decision.

H. Selecting a Surrogate Decision-Maker

1. If a patient is not capable of making health care decisions for himself or herself (as determined by the patient's primary physician), a surrogate decision-maker should be identified.

(i) If a patient has appointed a surrogate decision-maker (*e.g.*, in a durable power of attorney for health care) then the surrogate stands in the shoes of the patient for purposes of making health care decisions. Note that a surrogate appointed under a general power of attorney may not have authority to make health care decisions for the patient.

(ii) If a patient is under a conservatorship, the physician or facility should determine whether the conservator has authority to make health care decisions on behalf of the conservatee.

(iii) If the patient is an unmarried and unemancipated minor, then the patient's parent or guardian should make decisions for the patient.

(iv) If the patient is an adult and does not have a DPAHC, then it is customary to look to the patient's spouse, adult children, parents, or siblings to make decisions on behalf of the patient. Note that California law does not specify an order of priority for choosing a surrogate decision-maker.

2. The surrogate decision-maker must be guided by the patient's previously-expressed wishes, if known. If the patient's wishes are not known, the surrogate decision-maker must act in the patient's best interests.

I. Competent Adult Patients

Competent patients have the right to make their own decisions concerning proportionality. A competent patient may refuse any or all medical treatment, including the administration of food and fluids by artificial means.

J. Incompetent Adult Patients Without Advance Directives

If the wishes of an incompetent patient with respect to cardiopulmonary resuscitation or withdrawal or withholding of other life-sustaining treatment are known, they should govern the decision. If the incompetent patient's wishes are not known, it may still be appropriate to withhold or to withdraw treatment that is disproportionate, pursuant to the direction of an appropriate surrogate decision-maker for the patient.

K. Incompetent Patients With Advance Directives

Whenever a surrogate has been designated, or a patient has expressed certain wishes concerning life-sustaining treatment in an advance directive, the name of the surrogate and/or a copy of the advance directive should be obtained and placed in the patient's medical record. Absent a clear controversy, whomever is designated as the surrogate decision-maker under an advance directive shall be the decision-maker subject to the guidelines set forth above.

L. Unemancipated Minors

1. Unemancipated minors under the age of 18 years are legally incompetent to refuse life-sustaining procedures, and any such decision must be made by the minor's parents or by a legally appointed guardian, if any. However, a mature minor (*i.e*. a minor who has some degree of understanding of his or her medical condition and course of treatment) should be a part of the decision-making process to whatever extent his or her abilities allow. Life-sustaining treatment should not be withheld from a mature minor unless the minor and the parent(s) or guardian agree.

2. If a physician believes that a decision by a parent or guardian to forgo life-sustaining treatment for a minor violates professional standards or clearly goes against the minor patient's best interests, a report must be made to the Department of Children's Services. Prior to the report being made the physician should inform the parents what the law requires and advise them that a report will be made.

M. Infants

1. For minors less than one year of age, and minors older than one year who have been continuously hospitalized since birth, who were born extremely prematurely or who have a long-term disability, federal statutes and regulations have created special definitions of child abuse (Baby Doe Regulations). These regulations prohibit the

withholding of medically indicated treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's reasonable medical judgment, will be most likely to be effective in amelioration or correcting the life threatening condition.

2. Treatment may be withheld where, in the treating physician's reasonable medical judgment:

(i) the infant is chronically and irreversibly comatose;

(ii) the treatment would:

(a) merely prolong dying;

(b) not ameliorate or correct all of the infant's life threatening conditions; or

(c) otherwise be futile with respect to the infant's survival; or

(d) the provision of treatment would be virtually futile in terms of the survival of the infant, and the treatment itself under such circumstances would be inhumane.

N. Conservatees

Whenever the patient has a guardian or conservator with the power to make health care decisions, a copy of the certified letters of guardianship or conservatorship must be obtained and placed in the patient's medical record.

O. Conscious Conservatees Without Advance Directives or Designated Surrogates

Due to the recent California Supreme Court decision in Conservatorship of Wedland (2001) 26 Cal. 4th 519, conservators cannot authorize the withdrawal or withholding of life sustaining treatment from a conscious conservatee absent "clear and convincing" evidence supporting the conclusion that the decision to withdraw and/or withhold is in accord with the wishes of the conservatee or in the best interests of the conservatee. Given the inherent difficulty in making such a determination, hospital administration should be consulted whenever a conservator proposes withdrawing or withholding life sustaining treatment from a conscious conservatee without an advance directive or designated health care decision-maker under the Health Care Decisions Law.

P. Requests to Forego Resuscitative Measures: "No Code" and "DNR" Orders

1. The terms "do not resuscitate," "DNR," "no CPR," "no code" or any other similar term refer to the suspension of the otherwise automatic initiation of CPR.

2. In all cases where the nursing staff finds a patient to be in cardiac or respiratory arrest, cardiopulmonary resuscitation will be initiated unless a DNR or equivalent order has been written on the patient's chart by the attending physician.

3. In the event that the attending physician determines that a DNR order may be appropriate or other life-sustaining treatment should be withheld or withdrawn, but the surrogate decision-maker, or a family member, or significant other disagrees, the order should not be written. Instead, cardiopulmonary resuscitation and other life-sustaining treatment should be implemented as required and the surrogate decision-maker, family members, or significant other should receive counseling and support, such as from the patient's physician, the hospital's chaplain, social services personnel, or other appropriate personnel. In the case of a minor, life-sustaining treatment, including cardiopulmonary resuscitation, shall not be withheld or withdrawn if one of the minor's parents disagrees with the order. In extreme cases where a surrogate decision-maker, family member, or significant other refuses to authorize a DNR order or the withdrawal or withholding of other treatment, despite clear indications for such, hospital administration should be contacted to determine whether court authorization for withdrawal or withholding of treatment should be sought.

4. All existing DNR orders are automatically suspended when a patient undergoes an invasive diagnostic or therapeutic procedure. However, when an invasive diagnostic or therapeutic procedure is in the best interest of a patient with a DNR order, the physician obtaining consent for the procedure must discuss the patient's wishes concerning resuscitation in the event of cardiopulmonary failure during the procedure. If the patient and physician decide that an intra-procedure DNR order is appropriate, such order shall be specifically documented in the patient's chart. If no such intra-procedure DNR order is documented, resuscitative efforts shall be applied automatically in the event of cardiopulmonary failure during an invasive diagnostic or therapeutic procedure.

5. Even when a "do not resuscitate" (DNR) order is in effect or other life-sustaining treatment is withdrawn or withheld, the dignity of the patient must be preserved and all necessary measures must be taken to assure comfort.

6. A physician has the right to decline to issue a DNR order, and other orders for the withdrawal or withholding of treatment. In exercising this right, however, the physician must take appropriate steps to transfer the care of the patient to another qualified physician.

III. HOT ISSUES

A. Determining Capacity

1. It is the responsibility of the patient's primary physician to determine whether the patient has capacity to make health care decisions.

"Capacity" means a patient's ability to understand the nature and consequences of proposed health care, including its significant benefits, risks, and alternatives, and to make and communicate health care decisions.

2. The patient's "primary physician" means the physician designated to have primary responsibility for the patient's health care.

3. Patients are presumed to have capacity.

B. Choosing a Surrogate for Incompetent Patients With No Advance Directive

1. California law provides no guidance as to who has priority to act as surrogate.

2. Difficult cases occur when family members disagree or there is reason to believe there may be ulterior motives.

C. Revocation of Advance Directives

1. A patient may revoke designation of an agent only by signed writing or by personally informing the supervising health care provider. Patient must have capacity to make revocation.

2. A patient with capacity may revoke all or part of an advance directive (other than designation of an agent) at any time and in any manner that communicates an intent to revoke.

3. If the principal's spouse is the designated agent and the marriage is dissolved or annulled, the agent's power to make health care decisions is revoked.

D. Immunities and Liabilities

1. A health care provider or health care institution is protected from civil or criminal liability if they acted in good faith to comply with the patient's health care decision or the decision of a person they believed had the authority to make health care decisions for the patient.

2. Not criminally or civilly liable if the health care provider or institution failed to comply with health care decision or instruction based on reasons of conscience.

3. Intentional violation is subject to liability for damages of $2500, or actual damages resulting from the violation, whichever is greater, plus reasonable attorneys' fees.

4. A person who intentionally falsifies, forges, conceals, defaces, or obliterates an advance health care directive, or revocation without the person's consent, or inducement to give, not give, or revoke an advance health care directive is subject to damages up to $10,000 or actual damages from the action, whichever is greater, plus reasonable attorneys' fees.

5. A person who alters or forges another's advance health care directive with the intent to withhold or withdraw health care necessary to keep the person alive contrary

to the patient's wishes, which hastens the patient's death, is subject to prosecution for homicide.

E. Advance Directives for Psychiatric Services

1. New forms published by Protection and Advocacy, Inc.

IV. RESOURCES

A. The Consent Manual, published by the California Healthcare Association

B. Statutory Form DPAHC at Probate Code Section 4701